

February  
2019

# ASAP Connections

Providing Research, Education and Support since 1988

## Save the Date

**ASAP's Chiari & Syringomyelia Conference**  
**Together Towards Tomorrow**  
**July 24-27, 2019**  
**Philadelphia, PA**

Wednesday, July 24

6:00 PM – Registration and Buffet  
8:30 PM – Support Group Breakouts

Thursday, July 25

7:00 AM – Breakfast  
8:00 AM–5:00 PM – General Sessions

Friday, July 26

7:00 AM – Breakfast  
8:00 AM–4:00 PM – General Sessions  
6:00 PM – Cocktail Hour  
7:00 PM – Banquet with Silent Auction and Raffle

Saturday, July 27

7:00 AM – Breakfast  
8:00 AM–12:00 PM – General Sessions

Register online at [ASAP.org](http://ASAP.org) or call 903-236-7079

## Registration Reduced for Annual Meeting

ASAP has reduced the cost of registration to our 31st annual conference, thanks to a generous sponsor!

Not only is the registration fee lower but you also have the opportunity to attend for free.

How does that work?

Every paid adult registration for the ASAP Chiari & Syringomyelia Conference in Philadelphia will be placed into a monthly drawing. We will draw one name live at the end of February, March, April, May and June. That's five lucky registered members who get to attend for FREE! ASAP will waive the registration free that includes opening dinner reception (Wednesday), speaker presentations, daily breakfast and banquet dinner (Friday).

The earlier you register the more chances you have to win. Don't delay – Register today!

## 31st Conference Host



**Erol Veznedaroglu, MD, FACS, FAANS, FAHA**

*“During the middle of the 1700s, a number of American medical firsts took place in Philadelphia—the first hospital (Pennsylvania Hospital, 1751), the first anatomical lecture (William Shippen, Jr., 1762), and the first medical school (University of Pennsylvania, 1765). It is my pleasure to host the 31st Annual ASAP Chiari & Syringomyelia Conference and welcome you to the City of Philadelphia. I look forward to seeing you in July.”*

Board certified in neurological surgery, Dr Vez is a fellow of the American College of Surgeons (FACS), the American Association of Neurologic Surgeons (FAANS) and the American Heart and Stroke Association (FAHA). He has served on the ASAP Board of Directors and is currently serving on the ASAP Medical Advisory Board.

One of the nation's most innovative and experienced vascular, dual-trained neurosurgeons, he is director of the Drexel Neurosciences Institute and holds the Robert A. Groff Chair in Neurosurgery. Dr. Vez is also chair of Global Neurosciences Institute, LLC (GNI) leading a team of some of the nation's most experienced neurosurgeons specializing in comprehensive care including vascular, tumor, spine and functional neurosurgery, as well as a consortium of neuroscience physicians providing subspecialty neurology and comprehensive pain management clinical services. This consortium includes experts in Alzheimer's disease, Parkinson's disease, comprehensive pain management, epilepsy, headache, pediatric neurology and autism. GNI is transforming the way neurologic treatment is delivered to patients in New Jersey and Pennsylvania.

## Syngomyelia Awareness

May is Syngomyelia Awareness Month! Start making plans now to do something special during the month of May to promote awareness of Syngomyelia! Take photos of your event or project and email to the ASAP office (info@ASAP.org).

Suggestions for promoting awareness:

- Have your governor or mayor declare May as Syngomyelia Awareness Month with a proclamation. This is a newsworthy event. Get media coverage of you receiving the document.
- Get your local paper to publish a story about Syngomyelia. Local papers are always looking for personal stories for their Lifestyle or Health section.
- Plan a walk or awareness event in your town.
- Start a social media campaign to spread awareness. Try to post a new message every day to share facts about Syngomyelia.
- Give a presentation about Syngomyelia at your local schools, social clubs (Lions, men or women's Clubs, etc.) and groups.
- Have your scout troop learn about Syngomyelia.
- Share information with classmates, co-workers, neighbors, church family and friends.
- Make a YouTube video and tag ASAP.
- Tweet #maysyngomyeliaawarenessmonth
- Learn more about Syngomyelia. Knowledge is power!
- Honor someone with Syngomyelia through a donation to ASAP.
- Get your employer involved in a workday giving program.

## Contact Information

### American Syngomyelia & Chiari Alliance Project

#### Mailing Address:

PO Box 1586  
Longview, TX 75606-1586

#### Physical Address:

300 North Green Street, Suite 412  
Longview, TX 75601-7337

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**Fax:** 903-757-7456

**Toll-free:** 800-ASAP-282

**Email:** info@ASAP.org

#### Staff:

Patricia Maxwell

Patricia\_Maxwell@ASAP.org

Jamie Mayhan

Jamie\_Mayhan@ASAP.org

**Life is 10% what happens to you and 90% how you react to it ...**

## Stamp Project

ASAP members and friends have been collecting postage stamps as a fundraiser since the early 90s. It is an easy and fun way to make a difference. Stamps are sold to collectors and stamp clubs with the proceeds going to support programs for the Chiari and Syngomyelia community.

Please send cancelled postage stamps that are in good condition (attached to envelope and trimmed with a 1/4 to 1/2 inch border around undamaged stamp). Forever, special occasion and foreign stamps are accepted as well as postcards. Nonprofit, postage meter and presort stamps are not collectable.

Mail stamps to:  
Charles Petkevich  
ASAP Stamp Project  
6202 SW 2nd Court  
Plantation, FL 33317



**Please Note: Articles in this newsletter are not intended as a substitute for medical advice and do not necessarily represent the viewpoints of the editor, Medical Advisory Board or Board of Directors. Please contact your doctor before engaging in any new therapy or medication.**

**www.ASAP.org**

**Visit us on the web and be sure to check out our YouTube and FaceBook groups.**



## A Word From Our President Eric J Berning

What is important to you? Is it health, wealth, happiness, family connections, fame, expertise? What motivates you and keeps you going every day? Often I have to ask myself these types of questions as I keep my

focus on the positive aspects of my life. There are so many of us who suffer silently (and sometimes not so silently!) with Chiari, Syringomyelia, and other related conditions, yet we forge on the best we can. Sometimes it seems an insurmountable hill to climb, the weight of our conditions feeling akin to the resistance of Sisyphus' boulder. It's easy to succumb to thoughts that we, like Sisyphus, are caught in some sort of punishment and become overwhelmed with despair.

Growing up I was one of nine children. We didn't have much and made do with what we had. My parents did the best they could and instilled in us a belief in the power of positive thinking. I truly believe this is one of the most integral reasons I am able to do what I do with my life, given the limitations I work within. A positive attitude, my firm belief in my faith, and a healthy dose of "obnoxious" stubbornness give me the strength I need to persevere through the tough times and pain.

How can we stop that boulder from rolling over us? Surround ourselves with positive people and thoughts. Do not dwell on all the negatives that accompany our conditions—we all know there are a lot, and that they're not a figment of our imaginations. However, focusing strictly on the negative takes a far greater toll on our spirit and physical well-being than we can imagine. Do not let it. Self-reflection and motivation is very beneficial to maintain a positive mental attitude. It is difficult to get started if we have not conditioned ourselves to purposely seek out the positive aspects of situations. Our world thrives on the negative. The 24/7 news cycle is almost 99.9% negative; the constant bombardment from every direction of what is wrong with us or the world can be depressing and discouraging. It may take a concerted effort to seek and find the positive, let alone maintain and grow it. But we can do it!

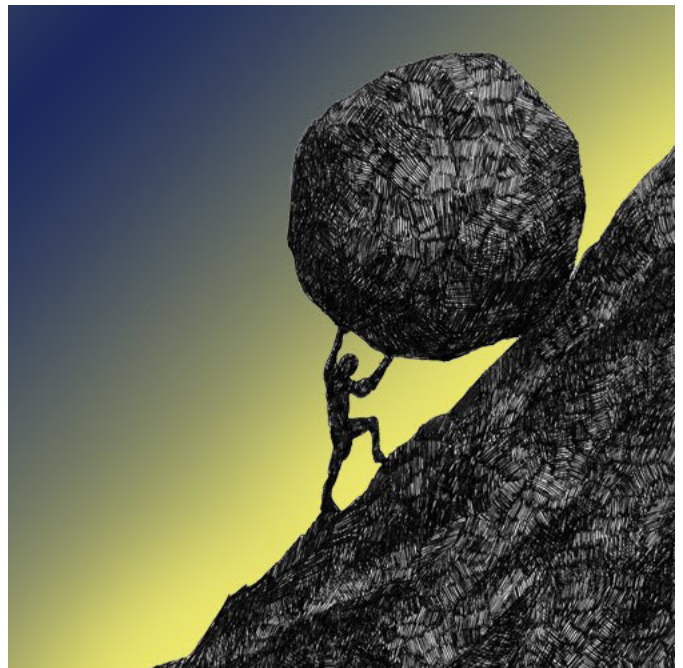
Start simply: leave yourself a note on your bathroom mirror to serve as a daily reminder of what is good in your world. Maybe even share it with others (our son wrote "You two are beautiful today" on a Post-It note and quietly stuck it to our bathroom mirror a year ago—it means so much to us, we keep it there!). Sharing a "warm fuzzy" with others is good for the soul! Expand it from there. You'll find yourself pushing the negative aside to accomplish what you wish. As I write this, I am experiencing one of those days when my pain is loud and clear, but with thoughts of sharing a positive message with you, I am choosing to focus on the good I might impart rather than feeling sorry for myself. This is

what I am trying to convey. While we live in a world of pain and discomfort, it does not have to define how we live our lives or how we perceive our lives. Enjoy the times when the pain is absent—or, at the very least, not overwhelming—and when it is there, try to turn your focus towards positive aspects of your life: memories, hopes, family, talents, whatever it may be that brings you joy. You will find after 30 days of consistent effort, the changes are noticeable. When you come across negative people or situations, you will start realizing you're not focused on them, but looking forward to moving past them and on to better things.

The one thing in life that you have absolute control over is the way YOU react to things. EVERYTHING else has an external factor that influences it. You can control you and only you. Choose to react in a positive manner. It will not only change you, but everyone around you. Negativity breeds negativity. Be the flower breaking through the snow in spring. Be someone others can look to for support and encouragement rather than complaints and negativity. It won't always be easy, but it will always be worth it.

When someone asks me how I'm doing, I often respond, "Wonderful." The other day I was asked, "Are you ever not 'wonderful'?" I replied that yes, often I am fighting pain and discomfort, but saying that I am wonderful reminds me that I have been worse and that right now I am better than I was.

You do not have to be Sisyphus, struggling with that boulder. Be wonderful! That rock has no power over you. Live within your limits, but live a life that is limitless!



## Helpful Ways to Get Through Painful Days

### Stay Active

It is important to keep your body toned. Exercise can produce endorphins that research shows can help decrease pain levels. However, it is important to find the best form of exercise specifically for you. Talk with your doctor or physical therapist to develop a program that will allow you to strengthen your body without increasing your symptoms.

### Get Plenty of Rest

Our body repairs itself during sleep. You should wake up refreshed. If you are not getting the proper amount of sleep, try to determine the cause and correct the issue. You may need to consult your doctor about tests or medication that will help you get the rest you need.

### Eat Healthy

The foods we put into our bodies can affect us in multiple ways. Many individuals have food allergies that they are unaware are causing symptoms or increasing other symptoms. Talk to a nutritionist to create a food plan that will help you stay stronger, decrease symptoms and provide consistent energy levels throughout the day.

### Ask for Help

For many asking for help is next to impossible but you might find people are eager to do things for you when given a chance. Make a list of things you need to do next week and see if you can find others to take on part of the task.

### Spend Time Each Day on Fun Activities

It is important to spend time doing things you enjoy. Whether it is crafts, reading, watching a movie or spending time with friends, you need to schedule your day with periods of activity and rest. You don't have to clean the entire house before you sit down for a visit. Know your limits and work with them to achieve realistic goals.

### De-Stress

Did you know that stress could increase pain? Learn to deal with everyday stress through meditation, music and relaxation.

### Share with Family and Friends

It is important to let others know how you feel. Unfortunately, they may feel the need to offer remedies. Let them know you are not looking for a cure (although one would be great). You just need someone to listen and understand.

### Find a Support Group

For many people, a health-related support group may fill a gap between medical treatment and the need for emotional support. A person's relationship with a doctor or other medical personnel may not provide adequate emotional support, and a person's family and friends may not understand the impact of a disease or treatment. A support group among people with shared experiences may function as a bridge between medical and emotional needs.

### Yogi's 4th Annual Community Fun Day

**Sunday, June 2, 2019**

**11:00 AM - 4:00 PM**

**Seneca Falls Elks Lodge #992**

**Seneca Falls, New York**

**Chicken BBQ 11:00 AM until sold out  
Games and Activities for the whole family  
Silent Auction, Raffle and Door Prizes**

For more information contact Michael "Yogi" Borys  
Email: [mbborys0903@gmail.com](mailto:mbborys0903@gmail.com)  
Phone: (315) 651-2657

### Molly's 5th Annual ASAP Walk & Roll for A Cure

**Saturday, September 21, 2019**

**10:00 AM**

**Bretton Woods Recreation Center**

**Germantown, Maryland**

**Walk starts at 11:00 AM  
\$5 lunch meal deal  
(burger or hotdog, drink and chips)**

For more information contact event organizer,  
Molly Lichtenstein at [molly\\_lichtenstein@ASAP.org](mailto:molly_lichtenstein@ASAP.org)

## Ehlers-Danlos Syndrome

Ehlers-Danlos syndrome (EDS) is an umbrella term for a growing group of hereditary disorders of the connective tissue. The main symptoms include:

- loose joints
- highly elastic, velvety skin
- fragile skin
- skin that bruises easily
- redundant skin folds on the eyes
- muscle pain
- muscle fatigue
- benign growths on the pressure areas (such as the elbows and knees)
- heart valve problems

Most EDS patients share a nearly normal life span, but are severely limited by disabling features, such as pain, fatigue and headache. Parents are often silent carriers of the defective gene that causes EDS. This means the parents may not show any signs of the condition and are unaware that they are carriers.

A series of tests may be used to diagnose EDS. They include genetic tests, skin biopsy and echocardiogram.

- An echocardiogram uses sound waves to create moving images of the heart. This will show the doctor if there are any abnormalities present.
- A blood sample is taken from your arm and tested for mutations in certain genes. A DNA test can confirm if the gene is present in embryos as well. This form of testing is done when the woman's eggs are fertilized outside of her body (in vitro fertilization).
- A skin biopsy is used to check for signs of abnormalities in collagen production. This is performed by removing a small sample of skin and checking it under a microscope.

Current treatment options for EDS include:

- physical therapy (used to rehabilitate those with joint and muscle instability)
- surgery to repair damaged joints
- drugs to minimize pain
- Additional treatment options may be available depending on the amount of pain you are experiencing or any additional symptoms.

You should take these steps to prevent injuries and to protect your joints:

- Avoid contact sports.
- Avoid lifting weights.
- Put adequate padding on your child before they ride a bike or when they are learning to walk.
- Use sunscreen to protect the skin.
- Avoid harsh soaps that may over-dry the skin or cause allergic reactions.
- Use assistive devices to minimize pressure on your joints.

## Occipital Neuralgia

### What is occipital neuralgia?

Most of the feeling in the back and top of the head is transmitted to the brain by the two greater occipital nerves. There is one nerve on each side of the head. Emerging from between bones of the spine in the upper neck, the two occipital nerves make their way through muscles at the back of the head and into the scalp. They sometimes reach nearly as far forward as the forehead, but do not cover the face or the area near the ears; other nerves supply these regions.

Irritation of one of these nerves anywhere along their course can cause a shooting, zapping, electric, or tingling pain very similar to that of trigeminal neuralgia, only with symptoms located on one side of the scalp rather than in the face. Sometimes the pain can also seem to shoot forward ("radiate") toward one eye. In some patients the scalp becomes extremely sensitive to even the lightest touch, making washing the hair or lying on a pillow nearly impossible. In other patients there may be numbness in the affected area. The region where the nerves enter the scalp may be extremely tender.

### What causes occipital neuralgia?

Occipital neuralgia may occur spontaneously, or as the result of a pinched nerve root in the neck (from arthritis, for example), or as the result of prior injury or surgery to the scalp or skull. Sometimes "tight" muscles at the back of the head can entrap the nerves.

### How is occipital neuralgia diagnosed?

Occipital neuralgia can be diagnosed—and temporarily treated—by an occipital nerve block. For patients who do well with this temporary "deadening" of the nerve, a more permanent procedure may be a good option. These treatments include cutting the nerve surgically, "burning" the nerve with a radio-wave probe, or eliminating the nerve with a small dose of an injected toxin.

Obviously any procedure that deadens the nerve permanently is likely to leave some degree of permanent numbness in the scalp. A few patients may do well with procedures that "spare" the affected occipital nerve—a surgeon could decompress the nerve by removing any impinging muscles or scar tissue, or a pain specialist could implant an occipital nerve stimulator, a pacemaker-like device that stimulates the nerve with electricity resulting in tingling rather than pain.

Because all of these procedures are invasive, carrying some degree of risk of permanent complications, they generally first try to use medications to "calm down" the over-active nerves. Some patients respond quite nicely to non-invasive therapy.

[Information source - Johns Hopkins Medicine]

Remember ASAP..

## When It's Time to Remember Loved Ones

Our appreciation to everyone who made a recent donation to ASAP on behalf of their friends and loved ones.

We will send an acknowledgement card to individuals or families when you make a \$5 (or more) donation to the organization. Please indicate whether the gift is 'in honor of' or 'in memory of' and provide name and mailing address of the recipient.

### In Honor of Donor

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United Volunteers of Maine  
2018 HH Participation

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Berger Family Foundation, Inc.

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## Bits and Pieces

- Need help spreading awareness about Chiari and Syringomyelia? The ASAP office can provide bookmarks that give a basic definition of the disorders.
- ASAP provides scholarships for the annual conference on a limited basis to qualified ASAP members. Email info@ASAP.org for the application and guidelines.
- ASAP is a 501(c)(3) publicly supported organization. Donations are tax-deductible to the fullest extent of the law.
- Our Mission: to improve the lives of persons affected by Syringomyelia, Chiari malformation and related disorders while we find the cure.
- ASAP is governed by a volunteer Board of Directors. Interested applicants should contact Eric Berning, ASAP President, eric\_berning@ASAP.org

## 2018 ASAP Chiari & Syringomyelia Conference Videos

### Available Online

<https://www.youtube.com/channel/UCJHul2aTWLIjLBUulsJSWvg/videos>

or

Go to [www.asap.org](http://www.asap.org) and click on the YouTube icon in the upper right corner which will take you to our YouTube channel. Click on videos in the menu bar.

**“Courage doesn't  
always roar.  
Sometimes  
courage is the  
quiet voice at the  
end of the day,  
saying, “I will try  
again tomorrow.”  
– Mary Anne  
Radmacher**

**ASAP's Chiari & Syringomyelia Conference**  
**July 24-27, 2019**  
**Attendee Registration Form**

**Contact Information**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

*Additional Attendees Please add contact information if different from above. List each child's name and age.*

Name: \_\_\_\_\_

Name: \_\_\_\_\_

*List additional attendees and contact information if needed on back.*

Fees	Number	Sub-total
Adult registration by July 10 *	_____ x \$160.00	_____
Children's registration: ages 5 - 15 *	_____ x \$ 65.00	_____
Additional banquet tickets: **	_____ x \$ 60.00	_____
Family pack: 2 adults, 2 children (ages 5-15)*	_____ x \$400.00	_____
Day rate: Circle day Thursday, Friday or Saturday	_____ x \$ 50.00	_____

\*Includes Wednesday reception, Friday banquet & breakfast (Thursday, Friday, Saturday)

\*\* For those who will only attend the banquet on Friday evening

Special diet request (vegetarian, gluten free, etc): \_\_\_\_\_

*Note: By submitting this form and/or attending the conference, you agree to allow ASAP to use photographs and/or videos taken of you in ASAP's promotional materials. You understand that ASAP will not publish or record any personally identifiable information without your express written consent.*

**Payment Information**

I want to make a donation. Scholarship Fund \$ \_\_\_\_\_ Conference Sponsor \$ \_\_\_\_\_

Check enclosed payable to ASAP, Inc. TOTAL PAYMENT: \_\_\_\_\_

Credit Card  MasterCard  Visa  Discover  American Express

Card # \_\_\_\_\_

Name of Cardholder \_\_\_\_\_

Signature \_\_\_\_\_

Expiration Date \_\_\_\_\_ Security Code \_\_\_\_\_ Amount \$ \_\_\_\_\_

**Return completed form with payment to ASAP, PO Box 1586, Longview TX 75606-1586**



**ASAP's Mission:** to improve the lives of persons affected by Syringomyelia, Chiari malformation and related disorders while we find the cure.

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**ASAP Connections**

The American Syringomyelia & Chiari Alliance Project (ASAP) is a tax-exempt 501(c)(3) organization. Our goals include providing a clearinghouse for information on Syringomyelia (SM), Chiari malformation (CM), and related conditions.

We offer a supportive network of programs and services and fund research to find better therapies and cures. ASAP is supported by tax deductible donations.

*ASAP Connections* is published quarterly for ASAP members. Your contributions of articles, letters, and photos are encouraged. The editor reserves the right to edit any article in order to accommodate space.

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